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The (non)charisma of noncommunicable diseases

Abstract

This paper uses the idea of a "charismatic gap" to help explain the disjuncture between the burden of disease attributable to noncommunicable diseases (NCDs) in the global south and a tendency to view this as something of 'an esoteric distraction from more pressing concerns in global health' such as HIV/AIDS, malaria, TB, vaccination and maternal health (Livingston, 2012, 9). NCDs are a composite category of cardiovascular disease, respiratory diseases, cancer and diabetes grouped together by virtue of four shared risk factors (tobacco, alcohol, unhealthy diets and sedentarism). While infectious diseases spread through viruses or bacteria under conditions of contagion that can provoke fear, disgust, suspicion and irrationality amid physical suffering and high mortality rates, NCDs have too often been met with ennui. This paper draws on the concept of charisma to help explore and explain the 'neglected epidemic' of NCDs in the global south through four themes: The lexicon used to describe, frame and communicate NCDs; risk factors and culpability; the temporality of disease; and its embodiment. In conclusion, the paper reflects on how to activate the latent charismatic potential of NCDs in the global south.

Keywords: noncommunicable disease, charisma, advocacy, credibility, global health

Introduction

In August 2014, I was in Gaborone, the capital of Botswana, coordinating a research project on the impact of consistent increases in the national liquor levy on drinking practices. At the end of a meeting, Thato (one of the research assistants) recounted how a male bar patron had criticised the research topic. Really, he had said, 'we should be talking about Ebola: that is the real threat to our lives, not alcohol'. At this time, Southern African countries were on high alert over a possible outbreak and Botswana's government was adopting a particularly cautious line. In August, Botswana closed its Zambian border due to fears of transmission from the Democratic Republic of Congo along copper export trucking routes. It also imposed a travel ban on all affected West African countries in defiance of African Union advisories, the Ministry of Health was replete with Ebola awareness posters and all air passengers were being screened for fever. Then in September, national tourist board officials pulled out of a large regional expo in Zimbabwe concerned by Harare's lack of Ebola

testing capacity. Even at the micro-level of the bar, the disjuncture in risk perceptions between alcohol which is a component cause of more than 200 diseases, accidents and injuries and roughly 3.3 million annual deaths worldwide (World Health Organisation, 2011b) and Ebola which, as I write in April 2015, has claimed almost 11,000 lives in seven countries is striking. That a virus with a mortality rate as high as 90% should command fear and awe is obvious, especially with emotive global media imagery of African Ebola patients and healthcare workers in hazmat suits (Rowell, 2014). Global fears ignited as the World Health Organisation (WHO), United Nations (UN) and NGOs screamed of "global crisis" as the epidemic transformed from a distant thing "of there" to one "of here" as it spread from West Africa to Europe and the US (Kluger, 2014). In being so 'sublimely awful' (*ibid),* Ebola is also devastatingly charismatic. It is this notion of charisma in relation to disease that is the central focus of this paper.

In essence, I want to use the lens of charisma to unpick a punitive and persistent conundrum: why 'the biggest global health challenges are not necessarily those that make the biggest headlines' (The Economist, 2015). To do this requires examining why and how certain diseases become imbued with sufficient charisma to garner public attention, material resources and political prioritisation, while others do not. Put another way, I share Roger Magnusson's concern with why 'the attention that lifestyle-related, noncommunicable diseases (NCDs) have received… is grossly disproportionate to the share of global death and disability they represent' in the global south (2007, 4). This disjuncture is further perpetuated because despite accounting for roughly 80% of premature deaths in low and middle-income countries (LMICs) (Siegel et al., 2013), NCDs still get only 2% of Gates Foundation global health spending (Robert et al., 2010). The WHO lists the four main chronic diseases as cardiovascular disease, respiratory diseases, cancer and diabetes. These are grouped together by virtue of sharing four "modifiable" risk factors: tobacco, alcohol, unhealthy diets and sedentarism (2010b). This classification presents NCD risk factors as a complex composite of material goods (alcohol, food, tobacco) supplied by 'corporate vectors of disease' (Gilmore et al., 2011), human behaviours (smoking, drinking, eating, and exercising) and other somatic risk factors (e.g.

hypertension). By contrast, infectious diseases may be embodied by humans, but their pathogens – whether viruses or bacteria - are distinctly nonhuman. Here the nonhuman "other" only adds to the high levels of fear, disgust, suspicion and irrationality that tend to circulate around highly contagious diseases that cause huge physical suffering and have high mortality rates (see for example Pappas et al., 2003; Wald, 2007). This affective response contrasts markedly with the ennui too often generated by NCDs in the global south, where the disease category tends to be viewed as something of 'an esoteric distraction from more pressing concerns in global health' such as HIV/AIDS, malaria, TB, vaccination and maternal health (Livingston, 2012, 9).

To explore the role of charisma in explaining this contrast, this paper proceeds in three parts. First, it examines how NCDs have come to be defined and classified and, how this has facilitated their construction as a 'neglected epidemic' in the global south that demands a fundamental shift in global health programmatic priorities (Horton, 2005). Second, the paper sets out how Weber's concept of charisma might be applied to the domain of disease and illness to help shed light on the meanings, values and affective responses that circulate around NCDs that in turn, complicate efforts to create 'credible and salient frames to support political and material prioritisation' (Jönsson, 2014, 8). I then trace the contours of this failure through four themes: (i) The lexicon used to describe, frame and communicate NCDs; (ii) the intersections of risk factors and notions of culpability; (iii) the temporality of disease; and (iv) their embodiment. This provides the basis for a final reflection on the future charismatic potential of NCDs.

Chronic disease: a global "challenge of epidemic proportions"

The Political Declaration adopted at the 2011 UN High-Level Meeting on NCDs expressly notes that they are a socio-economic and development '*challenge* of epidemic proportions' (United Nations, 2011, emphasis added). This label reflects their disproportionate contribution to the global burden of disease (Bloom et al., 2011; Stuckler & Basu, 2013) and their complex intersections with forces such as urbanisation and globalisation. Importantly, the language also contrasts sharply with NCDs'

conscious omission from the major programmatic priorities of global health (McCoy et al., 2009). In part, the burgeoning NCD rate in the global south is an unintended 'paradox of success' from efforts to reduce infectious disease mortality and morbidity, infant and maternal mortality, and gains made in life expectancy at the expense of years of life lived in good health (Varmus & Trimble, 2011; Worthman & Kohrt, 2005). NCDs are the leading global cause of death, with cardiovascular disease killing over 17 million people a year, cancer 7.6 million, chronic respiratory disease 4.2 million and diabetes 1.3 million, together accounting for 63% of the 57 million deaths globally in 2008 (Siegel et al., 2013). Beyond epidemiological quantification, NCDs pose a complex conundrum in countries of the global south for several reasons. First, NCDs in LMICs have fundamentally different trajectories than in High-income countries (HICs) as people 'get sicker sooner and die earlier than their counterparts in wealthier societies' (World Health Organisation, 2010b v). NCDs tend to be detected at a far later stage than in HICs, often at a point where scarce hospital care may be needed for complications or acute events. They also have a marked impact on those of working age (rather than old age in HICs) and estimates suggest that they could depress global economic output by $47 trillion (or 75% of global GDP) over the next 30 years (Bloom et al., 2011).

Second, where Universal Health Coverage does not exist or is insufficient, people are forced to cover the catastrophic expenses associated with diseases such as cancer or heart disease out of pocket. This leads to financial distress, deepens inequalities, threatens security and jeopardises development prospects (World Health Organisation, 2010b, v). For this reason, WHO warns that 'the epidemic already extends far beyond the capacity of lower-income countries to cope… [and] will reach levels that are beyond the capacity of even the wealthiest countries in the world to manage' (*Ibid*). Third, NCDs in LMICs pose a fundamental threat to human health and wellbeing and are thus a vital challenge to the attainment of the health-related Sustainable Development Goals (within which there are now nine targets expressly relating to NCDs). They also undermine the potential to realise the linked promises of a 'just, equitable and inclusive' world, 'committed to work together to promote sustained and inclusive economic growth, social development and environmental

protection' (United Nations, 2013). The NCD burden and its unequal socioeconomic and geographic distribution thus invoke crucial questions of human rights and social justice.

The magnitude of NCDs relative to their political prioritisation as well as their relative prestige within the world of medicine (Album and Westin, 2008) has led to accusations of 'malignant neglect' (Stuckler & Basu, 2013) by suggesting that the epidemiology, aetiology and broader consequences of NCDs are not only largely misunderstood, but also ignored within global health paradigms (Shiffman, 2009, 609). The main misconception among policy makers is often that 'NCDs afflict mainly the wealthy [or are] problems solely resulting from harmful individual behaviours and lifestyle choices, often linked to victim "blaming"' (World Health Organisation, 2010b, ix). The 'disconnect between the NCD experts… and non-experts' (Sridhar et al., 2011, 4) also means that understandings of the relationship between socioeconomic and political contexts and risk/vulnerability to NCDs is limited (Moser, 2011). This means that 'overcoming such misconceptions and viewpoints involves changing the way policy-makers perceive NCDs and their risk factors, and how they then act' (*Ibid*). Primary among this is recognising not just that NCDs are diseases of both the rich and poor in developing countries, but also that 'boundaries between communicable and noncommunicable diseases are often indistinct' (Farmer et al., 2013, 321). New syndemics are emerging where NCDs such as, for example, cervical or liver cancer have infectious aetiologies and chronic conditions such as type-2 diabetes can significantly increase the risk of otherwise infectious diseases such as TB (Singer & Clair, 2003). These co-infections are most marked amongst the NCDs of the world's "bottom billion" many of whom live in locations where TB is endemic, HIV rates are high and rates of obesity (as a risk factor for type-2 diabetes) are rapidly rising. In this sense, the WHO classification of NCDs as sharing four common "modifiable" risk factors is misleading both in an epidemiological sense and in its implicit suggestion that these risk factors are amenable to personal choice.

The charismatic potential of NCDs

Since Weber's theorisation of charisma, the term has been taken up as an analytical frame by a range of scholars seeking to understand the genesis and effects of power, agency and transformation across a range of contexts, social and political structures. Despite this proliferation, Smith argues that most engagements with Weber's 'complex conceptual edifice' have relied on reductionist interpretations which, in turn have 'cheapened and weakened' the application of this key sociological concept to a variety of empirical contexts (2000, 102). This critique is echoed by Blom Hansen and Verkaaik who contend that while the uptake of Weber's ideas have been manifold, the contemporary and 'dynamic social life of charisma stands in interesting contrast to the remarkably unchanging conceptualization of charisma in the social sciences' (2009, 7). With these concerns in mind, it is worth then briefly returning to Weber's original ideas before sketching out how these might provide a conceptual means by which to unpick why chronic disease, for all its *quantitative* measures of severity, so often fails to ignite a commensurate response in affective, political or financial terms. In Weber's terms, charisma arises as a form of (often extraordinary) exception, a welcome antidote to a widespread disenchantment with the rationalised forms of social order that characterises bureaucracy. Charisma is something possessed by individuals, bestowed and reinforced by the actions, needs and contexts of a society, and which ultimately produces political power, popular support and influence (Weber, 1947). Individual charisma then often emerges to fill a leadership vacuum at a time of crisis or uncertainty and finds success, in Weber's language, through being personalised, spontaneous, direct and inter-personal (2013, 52). This stands in contrast to the disengaged and often impersonal nature of rational-legal authority and bureaucratic life, characterised by its tendency to transform the 'mystical and mysterious into laws, rules and regulations' and reify 'common sense and generalised ideas' into forms commensurate with 'categorisation, management, forecasting, insurance and prevention' (Farmer et al., 2013, 24). The scientific method and epidemiology are two clear examples of the rationalising tendencies of bureaucracy in their efforts to calculate, categorise and standardise the indelible complexities of human experience and embodiment.

More recent analysis has explored charismatic leadership as a productive and performative force across a variety of human and nonhuman contexts. For example, Blom Hansen and Verkaaik's (2009) exploration of the 'charismatic potential' of the city distinguishes between what they term 'mythical' and 'performative' charisma. In the former, cities cultivate unique mythologies through a variety of discursive and material modes (e.g. guidebooks, advertising, the media, popular culture) which in turn endow their residents and spaces with unique forms of agency and symbolic power. This, they suggest, is the charisma *of* the city. Performative charisma, that occurs *in* the city, is produced instead through 'special forms of knowledge, networks, connectedness, courage and daring that enable some individual – politicians, gangsters, business tycoons and the everyday hustler – to assume leadership, or to claim hidden and dangerous abilities and powers' (2009, 9). The two are distinguishable, but also endlessly self-reinforcing in cities marked by constant states of potentiality and emergence. This clearly chimes with the ways in which charisma can be conceptualised in relation to disease. Here, 'mythical' charisma is generated by the interactions between popular and scientific knowledge, facts and anecdote, observations and rumour that come to circulate and characterise disease. 'Performative' charisma then evokes the types of knowledge, language, tools of persuasion and aspects of legitimation that enable certain individuals to talk of disease in ways that confer power and agency on that disease. Full charismatic potential lies in the symbiosis of the two typologies. The ascendancy of HIV/AIDS to global health priority is thus a clear example of where a disease itself assumed mythical charisma through discursive and material means (e.g. the use of metaphors such as "plague", the imagery of the AIDS orphan or the red ribbon) and performative charisma through the language and actions of certain individuals (e.g. Magic Johnson, Rock Hudson, Peter Piot, Bill Gates).

In Lorimer's (2007) work on the nonhuman charisma of 'flagship species', he distinguishes between three forms of charisma: ecological, aesthetic and corporeal. Ecological charisma relates to the ways in which organisms intersect with and can be comprehended by human bodies in ways that exhibit varying degrees of 'detectability' and therefore the ease with which they might be mapped,

researched and understood. Aesthetic charisma emerges from the very abrupt and immediate visceral affective responses to nonhuman behaviour and appearance in short-lived encounters. As Lorimer argues, aesthetic charisma relates in complex ways to the degree of alterity performed during those encounters, with the degree of difference often indirectly proportional to empathy engendered. Corporeal charisma, by contrast, emerges in practical interactions in longer-term engagements and processes that bring human and nonhuman into contact in a variety of settings, whether through research or happenstance. Both aesthetic and corporeal charisma are inherently malleable and dynamic and, importantly for this paper, can 'certainly be magnified through marketing and [are] open to a degree of construction', which may also be 'constrained by the ecological characteristics and particular agencies of the species themselves' (2007, 927). Diseases then, like organisms, have ecological characteristics through the social, economic, political, built and natural environments from which they emerge, are embodied and experienced (Rayner & Lang, 2012). Humans also interact with disease according to a variety of temporal dynamics – the speed of a heart attack to the long durée of diabetes – that in turn produce a range of affective responses from catastrophe to bleak resignation (Whyte, 2012). Together, these forms of charisma produce power and agency, but these are also experienced in dynamic ways, at different times and places. Charisma consequently cannot to be taken for granted, but Lorimer's work importantly shows that under certain conditions it can be cultivated.

Here then I want to argue that a "charismatic gap" is at the root of the 'legitimation challenges' facing NCDs in the manifold and multi-actor attempts to raise the disease category up global and national political agendas (Jönsson, 2014). Thus, 'the prioritisation of NCDs has not really benefitted from the *fear* or *empathy* that can be found in the security or social justice agenda in health. The development agenda has only belatedly been emphasised... In other words, there have not been any credible or salient frames to support political or material prioritisation' (Jönsson, 2014, 8). While *credibility* concerns authorial authority – whether by professional status, membership of an expert community, qualification or life experience – *salience* results from positioning claims such that they

resonate with the affective rhythms of people's daily lives (Benford & Snow, 2000). NCDs do not lack biomedical or epidemiological credibility, but the 'iron cage' of such rationalised framings may impede the kind of charismatic potential needed to generate salience. Credibility has been built up through, for example, the work of the NCD Alliance and the *Lancet's* series on NCDs which has moved from calls for attention to the 'neglected epidemic' (Horton, 2005), to bolder demands for 'urgent action' (Horton, 2007) and, in response to the Global Burden of Disease Study, demands for 'global action' to match 'global evidence' (Beaglehole & Horton, 2010). However, the NCD lobby's success in generating and sustaining credibility through appeals to epidemiological evidence has not yet found full expression in the reframing of global health priorities. Indeed, beyond the closed ranks of public health and biomedicine, NCDs in the global south remain painfully invisible, as yet lacking the kind of charismatic potential held by HIV or Ebola that ignited significant affective and material response. As Susan Sontag's seminal work on cancer (and then later AIDS), metaphor and meaning (1979) and Paula Treichler's (1988) work on 'epidemics of signification' remind us, how we write or talk of disease can never be benign. It is notable then that Maher and Sridhar contend that the global neglect of NCDs can be traced to a 'lack of strategic communication' (2012, 2), an aspiration that has been complicated by the very nature of the lexicon, causes, temporality and embodiment that characterise NCDs. I will explore these in turn below.

i. *Lexicon*

NCDs are a collective noun for a composite of four diseases and four behavioural risk factors. This terminology is important for, as Treichler reminds us, 'names play a crucial role in the construction of scientific entities; they function as coherent and unified signifiers for what is often complex, inchoate, or incompletely understood' (1999, 168). Thus, the term NCD may aim to simplify a compendium of complex diseases and aetiologies, but as Maher and Sridhar suggest, it is also 'a case study in poor branding… ("non")… fails to communicate that NCDs are in fact communicable: not just through infectious modes of transmission, but also through social norms and practices… a label that at first glance excludes social processes as a form of disease communication thus represents a major

impediment to the generation of priority' (2012, 10). Indeed, and as Sontag argues, 'any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance' (2001, 58). Yet, the bureaucratic significance afforded to NCDs *as a category* is arguably far less than the charismatic sum of its constituent diseases, especially in the global north. As Richard Smith asserts, 'non-communicable disease means nothing to ordinary people. Nevertheless, it seems as if the term—or rather its acronym, NCD—is becoming the accepted description' (2011).

The NCD category has thus emerged within public health in advance of any collective or popular understanding of its meaning or significance. This alone helps explain why 'iconic' diseases such as cancer (Livingston, 2012, 18), to which Sontag so clearly ascribes charisma (even if not explicitly named as such) can generate far greater political traction and public empathy when considered in isolation. Sridhar *et al* (2011, 2) sum up this semantic conundrum well when they ask, 'what is a noncommunicable disease? Although this question might seem straightforward and technical, it in fact attracts divergent responses. Inherently, the numerous definitions create confusion and a major communications and branding dilemma' (Sridhar et al., 2011, 2). The WHO definition is one attempt to overcome this divergence, yet this categorisation also erodes much of the cultural and political capital cultivated by the long-term efforts of advocates, lay-experts, patient groups, foundations and research organisations for component diseases such as breast cancer (Braun, 2003). This groundwork, which has been overwhelmingly concentrated in the Global North, has radically transformed the public relationship with *some* cancers. The NCD categorisation may then be a rational basis for the epidemiological surveillance and evidence-based policy, but by itself, does little to generate the affect, empathy or grassroots action that is both generative and an outcome of charisma.

ii. Risk factors, culpability and advocacy

In contrast to infectious diseases, the risk factors for chronic conditions tend to be yoked to four assumptions: (1) that individuals have and can exercise choice; (2) that choices exhibit varying

degrees of responsibility; (3) that behaviours are modifiable and (4) that the "wrong" behaviours reflect individual or class culpability (Herrick, 2011; Petersen & Lupton, 1996). These assumptions have been further entrenched by an overtly medicalised reading of NCDs focussed on individual exposure and treatment (see for example Sridhar et al., 2011) , rather than the more abstract and holistic ecological frameworks really needed to conceptualise and tackle the prevention of NCDs (Rayner & Lang, 2012). When framed as 'lifestyle diseases', discourses about the causes of NCDs are, as Sontag argues in relation to cancer, often 'used to express concern for social order' (2001, 72). In these ambivalent 'sites of social anxiety' (Ungar, 2001) we binge on food and alcohol, are irreparably distanced from the origins of our mass-produced, toxin-loaded food, we lead automated and automobile-reliant lives and allow children to be addicted to screens. The NCD risk factors consequently suffer from being socially normalised activities (eating, drinking and exercising) that are simultaneously objects of intense moral judgment. The risk factors for chronic diseases are thus dangerous vehicles for what Piper (2013) has termed 'voyeuristic class disgust' and subsequent 'reflexive positioning' in that they become mechanisms to judge the quotidian behaviours that we so often deny or discount in ourselves, rather than vehicles for the realisation of health equity and social justice. The risk factors for NCDs are thus far from exceptional. Moreover, the biomedical language in which they are described – risk thresholds, safe consumption, recommended daily allowances, target goals – only reinforces the cognitive dissonance between rationalised, quantified behavioural aspirations and the everyday pleasures of "risky" contemporary lifestyles.

The collective denial of the health impacts of our own behaviours may well stem from the inherent uncertainty and complexity of aetiological relationships between lifestyle (with the exception of smoking) and health. For example, the relationship between diet, exercise and body weight and between bodyweight and health are both unclear, and furthermore, intensely contested (Campos et al., 2006). Nutritional science is a field in which the state of knowledge not only seems to change daily (Nestle & Dixon, 2004), but is also inextricable from the interests of global multinationals (Stuckler & Nestle, 2012). Similarly, alcohol science is fraught with contradictions in its evidence

base, with individual country recommendations of “safe” consumption levels varying wildly and the debate over the purported benefits of “moderate” consumption showing little sign of being resolved (Yeomans, 2013). Together, these risk factors are not just precursors to disease, but also act as major cultural referents. In turn, their status as quotidian, normalised activities - in which most people lead lifestyles of varying degrees of “riskiness” and yet the progression of NCDs is often unpredictable - ironically engrains a culture of blame. In this, individuals are held to be responsible for their own poor health when they exercise the “wrong” lifestyle choices. This is far from the state of exception that characterises charisma and is also in marked contrast with HIV/AIDs where the elision of behaviour, blame and disease status became the basis for significant *lay* advocacy work (Brown, 1998; Farmer, 1993) whose success rested on the ability of its charismatic leadership to take up and subvert the language of rational-legal authority in order to challenge its punitive effects. By contrast, advocacy around the risk factors for NCDs has tended to emerge from faceless public health groups (e.g. Action on Smoking and Health in the UK) or industry-funded organisations (e.g. Drinkaware) which have thus far failed to catalyse *popular* movements for change in either the global north or south.

iii. Temporality

At the most basic of levels, a fundamental difference between NCDs and infectious diseases is that the former have to be managed through a complex catalogue of treatments often over very long timescales, while the hope is that the latter can either be prevented or eradicated through vaccination programmes or effectively treated with short-term drug therapies. This presents a major legitimation challenge for NCDs within current results-driven global health paradigms (Adams, 2013). Indeed, as De Maeseneer et al (2012, 1860) write, ‘describing the rising prevalence of NCDs as a “crisis” makes for good drama, but misleads us into thinking that this problem is amenable to a quick fix. NCDs represent a set of chronic conditions that will require sustained effort for many generations’. Despite the public health framing of NCDs as an issue of prevention, it is still the case that managing and treating chronic disease accounted for 75% of US health spending in 2012

(Centers for Disease Control, 2014). This can have incalculable social and economic costs, especially given that medical bills are the single most significant cause of individual bankruptcy in the US, even for those with insurance. Just as in the US, "catastrophic" healthcare expenditure is a major cause of household impoverishment in LMICs (Fassin, 2012), a situation only worsened by the fundamental inadequacies of care for NCDs. Many NCD treatments - e.g. statins or the polypill for cardiovascular disease or insulin for diabetes – require daily, lifetime adherence. These regimes aim to normalise treatment such that it becomes routine habit. However, this type of disease management may remove any sense of the disease being *exceptional,* eroding fear and compounding the discounting of future risk. Yet, as treatments themselves change, the boundary between acute infectious and chronic diseases is becoming ever more porous. HIV/AIDS serves as a powerful example of this and one of the clearest challenges to the global governance of NCDs as presently defined.

Reflecting on this challenge in a blog piece about the 2011 UN High-Level Meeting on NCDs, Laurie Garrett (2011) recounts that 'the most common phrase I heard mumbled around the NCD Summit was, "We have to learn from the HIV movement. We have to adopt their tactics to raise money"'. This then warrants a return to Sontag's words: 'the most terrifying illnesses are those perceived not just as lethal, but dehumanising' (2001, 126), which in turn evokes Lorimer's concern with 'corporeal charisma'. HIV/AIDS is then a clear example of the transformation of a lethal and dehumanising disease into a chronic manageable condition through the unremitting work of advocates, lay-experts and biomedical experts (Epstein, 1998). With expanded access to antiretroviral (ARV) therapy, life expectancies have increased and the HIV response has evolved into a chronic disease management challenge (Deeks et al., 2013; Nigatu, 2012). This challenge now means responding to the heightened risk of co-infection with chronic infectious diseases such as TB and NCDs such as cancer, diabetes, and cardiovascular diseases. Now there also increased risks of chronic disease co-morbidity from HIV infection, its treatment protocols and the ageing processes that had hitherto been impossible (Fisher & Cooper, 2012; Samaras, 2012). These shifts mean that much of the charismatic advocacy work founded on 'a sense of moral urgency, a fear of contagion, the risk of an exponential rise in cases,

and a mounting sense that HIV/AIDS constituted a new form of transnational security threat that could destabilise societies' (Sridhar et al., 2011, 6) has disintegrated. Max Pemberton's (2014) controversial *New Statesman* article may argue that he would 'rather have HIV than diabetes', but Strudwick's recent award-winning blog piece on the hidden lives of those with HIV (2014) reminds us that the stigma attached to HIV has not disappeared, but been reconfigured into new, punitive forms by diminished public awareness, interest and knowledge. This is a challenge to the quality of life gains enjoyed by those living with HIV across the globe. It also represents a significant threat to the future of global HIV advocacy and funding (Garrett, 2014; Jaffe, 2004; Jaffe et al., 2007).

iv. Embodiment

In this final section I want to think through the links between the embodiment of disease and the generation of Lorimer's notion of 'aesthetic' charisma. Maher and Sridhar have argued that 'NCDs lack a "human face"' in that individual suffering it is not immediately obvious by 'virtue of… physical appearance' (2012, 4). They go on to argue that 'NCDs have not yet been portrayed through the use of images and media clips that depict actual human suffering. This serves to dehumanise the issue, limiting its emotional appeal and, ultimately, its salience' (*Ibid*). The iconography of cancer in the global north, for example, has been brought out in popular culture from TV shows such as *Breaking Bad* and the *C Word,* to the bestselling book and movie, *The Fault in our Stars.* However, and as Julie Livingston asserts, all too often, cancer in the global south is not only rendered invisible, but deemed an 'esoteric distraction' from the more pressing concerns of global health. This is despite the scale of suffering that radiates from patients to their families, communities and state health and social care systems. Livingston's work in Botswana thus demonstrates how NCDs can produce a particularly visceral state of *exception* that disrupts social lives but reanimates the charismatic potential lost to biomedical nomenclature.

Livingston has argued that Botswana, like many other countries of the global south, exemplifies 'an epidemiological transition in which a rising tide of chronic illness and an AIDS epidemic live side by

side' (2003, 225). This has meant that while passing into old age once meant certain frailty and sickness, NCDs now mean that this is now occurring at far earlier life-stages than before. This state of 'early old age' has disrupted long-held understandings where age confers both cultural authority and the need for care. This shift is rendered even more socially and economically significant as life expectancies rise. Thus, while some Batswana enjoy the spoils of rapid post-Independence development, economic growth, urbanisation and greater material wealth, a situation has arisen in which 'the illnesses that identify patients as elderly are seen as emblematic of the generalised disorders of a new type of "modern living"' (2003, 213). This has produced a moral economy in flux, compromising traditional models of community care provided by older female relatives in rural homesteads as these carers begin to endure poorer health themselves. While these processes may be embodied in particular ways in Botswana; the co-existence of infectious and NCDs in households is a phenomenon that is replicated across the global south, with significant consequences for all tiers of life.

More recently, Livingston's work has explored the intersections between heath and the 'affective life', or as she describes, the 'disgust, and the fear, amusement or curiosity' that can accompany illness and touches all those who live with it (2008, 290). This has clear resonance with the construction of both corporeal and aesthetic charisma in relation to the embodiment of disease. In Botswana, there has long been a social concept of 'botho', roughly translated as 'humanity', or the dialectics of care that shape society. The disgust that often accompanies the very visceral and dehumanising features of cancer and its unmanaged pain in so much of the global south – and stands in contrast to the systematic management systems of oncology in the global north - 'reminds people of the social vulnerabilities of their own bodies' (2008, 291). In her 2012 work on the Gaborone cancer ward as a 'microcosm, an instantiation of global health' (181), Livingston explores how 'clearing away the cloud of AIDS [has] revealed a landscape of cancers' (xi). This silent "epidemic" she argues, is the 'the critical face of African health *after* anti-retrovirals' which 'exposes the unfortunate fact that biomedicine is an incomplete solution' (7). This assertion is important

because unlike cancer care in the global north, in most African contexts oncology proceeds as a form of 'improvisation', a bricolage of knowledge, skills, medication (where available) and care in the face of great suffering: rotting flesh; pungent odours; unremitting pain; pulsating tumours and other 'bodily obscenities' (Livingston, 2014). These 'obscene cancers of an oncological past' (2014, 12) are the ones that the 'fantasies of global health' (2012, x) do not allow us to see. There is charismatic potential in such awfulness, yet the rational bureaucracy of biomedically-led global health effectively silences this. The fear, awe, grief and sadness that accompany cancer in countries like Botswana instead remain a local concern, too often dissociated from oncological experiences in the north. The embodiment of NCDs would thus be far more compelling were it not so hidden.

Conclusion

This paper has explored the "charismatic gap" between the scale of the burden of disease attributable to NCDs and the limited uptake of the category within the global health enterprise. Without charisma, that is, the possession of an *exceptional* status that incites affective responses such as fear, anxiety, awe or disgust (Lorimer, 2007, 921), the potential political and popular salience of NCDs will remain limited, regardless of the power of the advocacy community's credibility claims. As Sontag and Treichler's work so clearly reminds us, the naming of a disease is of exceptional significance to the meanings that then come to circulate around those struck by illness. As Sontag writes, in some cases 'the disease itself becomes a metaphor. Then, in the name of the disease (that is using it as a metaphor), that horror it imposes on other things. The disease becomes adjectival' (2001, 58). This has clearly been the case with cancer and the evocative use of adjectives such as "cancerous" to denote risk, contagion, fear and social ills only serves to heighten the affective register of the disease. However, and as I have argued in this paper, the charismatic potential so cultivated by advocacy efforts in the global north is eroded when cancer becomes categorised as an NCD, an acronym that is largely meaningless outside the biomedical world. We must thus be attuned to the salience inherent in the language we use to describe and compare diseases. For example, Max Pemberton's bold statement that he would prefer to contract HIV than to be diagnosed with

diabetes attempts to reposition HIV from a source of fear to a relatively benign chronic manageable condition. Yet, in drawing out an express comparison between HIV and diabetes, the effect is really only to draw attention to diabetes' own lack of charisma. The 'cultural narratives' (Treichler, 1988, 66) that characterise individual chronic diseases can therefore be lost when they are demarcated as NCDs. There is no shared history of NCDs, no high-profile advocacy and few cultural connotations beyond the association of risk behaviours with lifestyle. This association, in turn, only evokes notions of individual and collective culpability that undermines the case for global action in the common good.

Charisma is fleeting and opportunistic. It can also be actively engineered through cultural, political and biological negotiations. The advocacy around cancer and HIV/AIDS is obviously exemplary in this regard, but this work also shows the future scale of the endeavour. WHO only officially recognised AIDS as a disease in 1986 and the Global Fund was not set up until 2002. Sridhar *et al's* 2013 report clearly highlights the fundamental differences between the political contexts of the first UN High Level Meeting on AIDS in 2001 and that of NCDs in 2011. These include: the lack of strategic leadership on NCDs; the effect of the global recession on willingness to spend on primary healthcare and health promotion; and the vested interests of the food, drink, tobacco, and pharmaceutical industries. While NCDs can be by-products of the spoils of development, they also co-exist with the infectious diseases of poverty and mark out the pernicious outcomes of inequality. Ironically then, rising rates of NCDs in the global south challenge our perceptions of life in those countries not by highlighting these differences, but rather how the quotidian behavioural risks discussed earlier in this chapter are now globalised, common and shared. This new normal should be contrasted with HIV/AIDS or Ebola which were cast as 'a strategic threat to societies and sovereign stability' (Sridhar et al., 2011, 6). Weber's work reminds us that charismatic potential dwells in spaces of opportunity generated by times of 'distress' or a rejection of routinized, bureaucratic life. However, at the scale of the global, there is little sense of threat from NCDs in the global south in the same way as, for example, Ebola. When *collective* distress is negligible, inaction and ineffective mobilisation are a

persistent reality. Charisma thus remains in a frustrating latent state. Activating this latency is the aim of the first global communications strategy from the WHO and NCD Alliance called *NCDs and Me* (http://www.who.int/ncds-and-me), which was launched in August 2016 and provides a web platform for showcasing individual stories of living with NCDs. The aim is to humanise, challenge stigma and change mindsets. Only time will tell how what this campaign achieves, but its very existence demonstrates the resilience of the "charismatic gap" that this paper has explored. However, if the devastating charisma of Ebola teaches the NCD movement anything, it should be that fear, awe and uncertainty may threaten scientific credibility, but they do generate the salience needed to catalyse political action.

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